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Tube and Intravenous Feedings

Tube and intravenous feedings can prolong life in patients who cannot take adequate nutrition by mouth. In conditions such as short bowel syndrome, parenteral hyperalimentation can allow patients to lead active lives for many years. However, in severe, progressive illness such as advanced dementia or metastatic cancer, tube and intravenous feedings might merely prolong death and subject patients to indignity. Nationwide, 34% of nursing home residents with severe cognitive impairment have feeding tubes (1).

CASE 18.1 Tube feedings in a patient with severe dementia (2).

A patient's daughter leaves a phone message: "My mother, Mrs. F, has eaten nothing all weekend. What should we do?" A 70-year-old woman with severe dementia, Mrs. F rarely speaks, is confined to a wheelchair, and requires diapers for incontinence. She has been kept out of a nursing home by the efforts of a devoted family and a geriatric day care center. During the past year her social actions have decreased and her food intake has become increasingly erratic. First she stopped feeding herself. Now, although her family feeds her by hand, her intake continues to decline. Once she required overnight hospitalization for dehydration. During the past week she has been clamping her mouth shut, pushing the spoon away with her hand, and spitting out food. Over the weekend even coaxing with her favorite foods was unsuccessful. Those who care for her must now face a dreaded question: If hand feedings continue to fail, should she be fed through a feeding tube? The situation evokes strong and conflicting reactions. The patient's sister says, "We can't let her starve to death!" The daughter, however, says, "She's telling us to stop. We're just torturing her."

REASONS TO PROVIDE TUBE AND INTRAVENOUS FEEDINGS

ALLOWING PHYSICIANS TO TREAT REVERSIBLE CAUSES OF FEEDING PROBLEMS

Decreased oral intake might result from reversible medical problems, such as intercurrent illness, mouth lesions, or side effects of medications. Psychosocial problems, such as a desire for more control, depression, or a change of caregivers, might also cause feeding problems. Sometimes making hand feedings more acceptable to the patient can address refusals to eat. The caregiver can slow the pace of feeding, offer smaller bites, alter the taste or consistency, remind the demented patient to swallow, or gently touch the patient (2,3). Temporary use of tube or intravenous feedings might resolve the crisis and allow the underlying problem to be identified and treated.

WITHHOLDING TUBE AND INTRAVENOUS FEEDING WOULD STARVE PEOPLE TO DEATH

Everyone has temporarily experienced thirst or hunger and can imagine how agonizing it must be to starve to death. Similarly, everyone appreciates how upset infants become when they are not fed. By analogy, some people believe that adult patients with terminal illness or advanced dementia suffer when feeding tubes are withheld. In addition, tube feedings clearly prolong life for years in persons in persistent vegetative state (PVS). Finally, some physicians believe that discontinuing tube or intravenous feedings makes them the direct cause of the patient's death.

TUBE AND INTRAVENOUS FEEDINGS ARE ORDINARY CARE

Many people regard tube feedings as basic humane care. In one survey, 16% of physicians agreed with this position (4). In this view, feeding is an essential part of caring for the helpless, just like providing a warm, clean bed (5). Tube feedings are also a means of expressing compassion, caring, and love.

WITHHOLDING TUBE AND INTRAVENOUS FEEDINGS WOULD LEAD TO ABUSES

Fears of abuses and slippery slopes cause some people to insist on providing artificial feedings. Suppose artificial feedings are withheld in a case in which the reasons seem compelling. This precedent might make it easier to withhold artificial feedings or other life-sustaining interventions in other cases, even if the reasons are not as convincing. The next patient's family might not be so loving, or the next physician might not be so careful about searching for treatable feeding problems. Eventually, life-prolonging interventions might be withheld in cases that would previously have been regarded as inappropriate. According to this line of argument, the only way to prevent such a loosening of standards is to prohibit the action under all circumstances.

REASONS TO WITHHOLD TUBE AND INTRAVENOUS FEEDINGS

Those who would allow artificial feedings to be withheld from patients with severe, progressive illness frame the issues differently. They agree that it is morally obligatory to give bottles to infants, provide groceries to homebound persons, and place spoonfuls of food in the mouth of a person with dementia. However, opponents offer several reasons for withholding tube feedings when patients such as Mrs. F refuse oral intake.

TUBE AND INTRAVENOUS FEEDINGS MERELY PROLONG DYING

Many people believe that tube and intravenous feedings only prolong death for terminally ill patients. They consider it inhumane to force-feed people with severe dementia or metastatic cancer only to have them succumb to pneumonia or some other complication. Furthermore, it is problematic to say that withholding artificial feedings causes the patient's death. Determining a *single* cause of death when many factors are contributing to the patient's death is a controversial philosophical topic (6). Nonetheless, in such cases death is usually attributed to the underlying dementia or cancer and not to the act of forgoing medical interventions—provided that the reasons for withholding treatment are ethically acceptable. Chapter 14 discusses these distinctions in detail.

SUCH PATIENTS SELDOM SUFFER IF TUBE AND INTRAVENOUS FEEDINGS ARE WITHHELD

Patients with severe dementia or metastatic cancer seldom experience thirst or hunger if they continue to refuse oral intake. In a study from a comfort care unit, almost all lucid, terminally ill patients reduced intake of food and fluids to less than their nutritional needs. About two thirds never experienced hunger, and about one third experienced hunger only initially. Symptoms of thirst or dry mouth were more common, with 36% experiencing them until death. In all patients small intake of food and fluids, ice chips, and meticulous mouth care relieved symptoms of hunger

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and dry mouth (7). In another study hospice nurses rated quality of death of patients who refused food and water as 8 on a 9-point scale, where 9 was a very good death (8). With reduced oral intake, symptoms such as nausea, vomiting, edema, cough, and incontinence are reduced (3). Furthermore, pain medications should be given if needed, just as they are provided to patients with respiratory failure who decline mechanical ventilation.

TUBE AND INTRAVENOUS FEEDINGS CANNOT BE CONSIDERED ORDINARY CARE

Labeling artificial feedings as "ordinary" care is questionable. Cessation of the desire for food and drink is part of the natural history of severe illnesses such as severe dementia or metastatic cancer. In other Western societies, such as the United Kingdom and Sweden, tube feedings are rarely administered to patients with severe dementia (9). In addition, long-term intravenous or nasogastric tube feedings have become technically possible only in the past 30 years. The Food and Drug Administration regulates artificial feedings as drugs and medical devices, not as foods. Furthermore, feeding gastrostomy or jejunostomy tubes require a surgical or endoscopic procedure for insertion.

More fundamentally, most writers on medical ethics and virtually all court decisions reject the distinction between "extraordinary" and "ordinary" care (*see* Chapter 14) (10–12). The issue is not whether an intervention can be considered "extraordinary" or "ordinary" but whether its benefits outweigh its burdens for the individual patient (11). As with other interventions, tube and intravenous feedings should not be provided simply because they are technically feasible.

TUBE AND INTRAVENOUS FEEDINGS HAVE BURDENS AND BENEFITS

Like all interventions, tube and intravenous feedings have burdens as well as benefits. For patients with severe dementia or metastatic cancer, the benefits of tube feedings are limited. Treatable conditions are identified and corrected in few such patients (13). One cohort study found that 50% of patients with severe dementia who receive tube feedings died within 6 months (14).

Recent articles argue that tube feedings do not prolong life in patients with severe dementia. This simple claim is misleading unless it is carefully qualified. First, such patients often die from infection or other comorbidities, which tube feedings do not address. Second, patients with advanced dementia might survive for extended periods while taking only small amounts of food and fluids offered by mouth. However, if they have no oral intake whatever, tube feedings prolong life in the sense that without them, patients die in 1 or 2 weeks.

The burden of tube feedings might be substantial. Complications of tube feedings in elderly patients include aspiration pneumonia in 46% of cases and agitation leading to self-extubation in 61% (15). Tube feedings might not reduce the risk of aspiration pneumonia compared with oral intake (15). Aspiration pneumonia appears to be as common with gastrostomy tubes as with nasogastric tubes (16). In one study of tube feedings in a nursing home, restraints were applied in over 50% of patients to prevent them from pulling out their feeding tubes. (13). Patients who pull out feeding tubes might be communicating refusal, expressing discomfort or anger, seeking attention or control, or acting in a purely reflexive manner.

Restraining demented patients to prevent them from pulling out tubes compromises their independence and dignity, particularly because they cannot appreciate how the feeding tube will help them (2). Restraints also increase patient agitation. Sedation or "chemical restraint," which might appear to be more acceptable, also compromises patient dignity. Many patients do not want to be restrained. In a study of nursing home residents, 33% said they wanted tube feedings if they were unable to eat because of permanent brain damage that also left them unable to recognize people. However, after learning that physical restraints are sometimes applied to patients receiving tube feedings, 25% of residents who initially wanted tube feedings or were not sure changed their minds and preferred not to have them (17).

CARE SHOULD BE PROVIDED DIRECTLY, NOT THROUGH SYMBOLS

If the goal of care is to provide comfort and compassion, caregivers should do so directly rather than through symbolic actions (2). This can be done by offering patients food and water by hand, moistening their mouth and lips, holding their hand, or giving a backrub.

Ironically, artificial feedings might be impersonal. With tube feedings the caregiver might focus more attention on technical issues, such as positioning the feeding tube and checking the residual volume, than on the patient. If tube feedings proceed without complication, social interaction between the caregiver and patient can be minimal. Moreover, the patient has no control over tube feedings except to pull out the tube. In contrast, with hand feedings patients determine the timing, pace, and even the content of feedings. Patients are in control if they turn away or clamp their mouths shut. Thus, hand feedings that provide inadequate nutrition might meet more of the patient's human needs than tube feedings that deliver adequate calories impersonally.

SLIPPERY SLOPE ARGUMENTS ARE UNPERSUASIVE

Slippery slope arguments shift attention away from the individual patient to future patients or to society as a whole. The patient's family and physicians might assert that the proper focus should be on what is best for the individual patient, not on what precedent is set. Under the guideline of beneficence, physicians should act for the individual patient's benefit, not for the benefit of third parties, such as future patients. It seems cruel to impose interventions that are not in the patient's best interests in order to protect other people from harm. A better approach would be to develop adequate safeguards to protect others.

Another rebuttal to slippery slope arguments is empirical: There is little evidence that withholding tube feedings from severely demented patients has led to inappropriate withholding of care in other situations.

Finally, slippery slope objections also apply to withholding any form of life-sustaining intervention. Singling out artificial feedings as leading to a slippery slope implicitly assumes that they differ in significant ways from other interventions. This distinction is untenable.

LEGAL ISSUES

According to court decisions, artificial feedings are similar to other medical interventions, which have benefits and burdens for the patient (12,18). The predominant judicial opinion is that artificial feedings are medical interventions that may be withheld under appropriate circumstances, not comfort measures that must always be given. In several states courts have ruled that tube feedings may be withheld from a patient's PVS or minimally conscious state only if there is clear and convincing evidence that the patient would refuse.

CLINICAL RECOMMENDATIONS

When patients with conditions such as severe dementia stop eating and cannot be fed by hand, physicians and surrogates need to discuss the goals of care as well as the benefits and burdens of tube feedings. Decisions are difficult when patients have not provided advance directives. If there are reversible problems that impair oral intake, temporary intravenous or tube feedings are appropriate. Long-term tube feedings are appropriate if patients have no irreversible life-threatening problems and would consider their quality of life acceptable. However, tube feedings are not indicated if the patient has serious, progressive illness and a poor quality of life and if a caring surrogate agrees that the goal should be to provide comfort.

Many cases will fall into a gray area. A trial of tube feedings might then be helpful. If they are well tolerated, the benefits probably outweigh the burdens. If the patient repeatedly pulls out a nasogastric tube, the goals need to be reconsidered. If prolonging life is still deemed the goal, a feeding gastrostomy or jejunostomy would be appropriate. Such tubes are less obtrusive than nasogastric tubes and more difficult to remove. Tying the patient down or sedating the patient to keep the tube in place is difficult to reconcile with the goal of providing humane care (2). Instead, it might be appropriate to withhold tube feedings. Food and water should still be offered by hand. However, compassion and comfort are better expressed through direct attention and affection than by forced feedings.

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Physician-Assisted Suicide and Active Euthanasia

Although traditional medical ethics prohibit assisted suicide and active euthanasia, public opinion and policies in the United States are divided. In 1994, Oregon legalized physician-assisted suicide. However, several states recently passed laws criminalizing physician-assisted suicide. In 1996 the Supreme Court ruled that there is no constitutional right to physician-assisted suicide and that states may prohibit it (1). Studies document that physician-assisted suicide and active euthanasia are carried out despite legal prohibitions (2). Two juries acquitted Jack Kevorkian, a nonpracticing pathologist who publicized numerous cases in which he assisted in a patient's suicide, before he was convicted of murder for administering a lethal dose to a patient.

DEFINING TERMS CLEARLY

Imprecise terminology and rhetorical slogans mar the debate on assisted suicide and euthanasia. Several actions should be distinguished.

ACTIVE VOLUNTARY EUTHANASIA

In active euthanasia the physician administers a lethal dose of medication, such as potassium chloride. The physician both supplies the means of death and is the final human agent in the events leading to the patient's death. Active euthanasia is sometimes called *mercy killing*. Euthanasia is called *voluntary* when the patient requests it, *involuntary* when the patient opposes it, and *nonvoluntary* when the patient lacks decision-making capacity and cannot express a preference. There is general agreement that involuntary euthanasia is wrong because it violates a patient's right not to be killed. Nonvoluntary euthanasia is also generally considered unacceptable because it might be applied selectively to the disadvantaged and the vulnerable.

ASSISTED SUICIDE

In assisted suicide the patient swallows a lethal dose of drugs or activates a device to administer the drugs. Physicians might assist in a variety of ways. They might provide the means for suicide, provide information on it, or refer the patient to the Hemlock Society for information.

Many people consider assisted suicide less ethically problematic than active euthanasia. Although the physician provides the means of death, the patient must carry out an independent act. This fact might have several important ethical implications. First, subsequent intervening action by the patient might lessen the physician's moral responsibility. In this view, patients who have free will are morally responsible for their acts. Although other people might influence the patient, they are not regarded as causing the patient's actions unless there is coercion. Second, the justification might be stronger

because taking an action to commit suicide is a more direct expression of the patient's autonomy than is a request for active euthanasia. Third, there might be less danger of abuse. If the patient changes his or her mind on suicide, he or she simply does not take the relevant pills. In contrast, a patient might feel pressure to go through with arrangements for active euthanasia.

Physicians, however, must not underestimate their moral responsibility if they assist a patient in committing suicide. The motive, intent, justification, and outcome are the same as in active euthanasia. In other situations people might be held morally responsible for assisting or encouraging another person to commit an immoral act.

Some physicians who prescribe a lethal dose of medications might claim that they did not know that the patient planned commit suicide. For example, some doctors might prescribe secobarbital upon a patient's request without discussing suicide. It would be disingenuous to abjure responsibility in this situation, however. Doctors almost never prescribe secobarbital except as a means for suicide. Most important, by not broaching suicide, physicians forego an opportunity to provide better palliative care, which often leads patients to change their minds on suicide.

WITHHOLDING OR WITHDRAWING MEDICAL INTERVENTIONS

Active euthanasia and assisted suicide are usually distinguished from withholding or withdrawing interventions, which are also termed *allowing to die* or *passive euthanasia*. Ethically and legally, medical interventions may be withheld or withdrawn if a competent patient or an appropriate surrogate refuses them (see Chapter 14). A patient's refusal of life-sustaining treatment is honored because patients have a right to be free of unwanted bodily invasions. Under such circumstances the underlying *illness*, not the *physician's* action or inaction, is considered the cause of death. Therefore, concern that assisted suicide or active euthanasia is improper should not lead physicians to impose interventions that the patient or surrogate does not want.

This distinction between killing and allowing to die provides practical guidance, but it is problematic for several reasons (3,4). First, some patients who refuse life-prolonging interventions want to hasten their death, not just to be free of unwanted medical interventions (5). Second, many philosophers have rejected the distinction between acting and refraining from action, pointing out that withholding effective treatment would be condemned if done against the patient's wishes or for malicious motives. However, even though *some* cases of foregoing life-sustaining interventions are hard to distinguish from physician-assisted suicide, it does not follow that *all* cases of foregoing life-sustaining interventions are equivalent to physician-assisted suicide.

ADMINISTERING APPROPRIATE DOSES OF OPIOIDS OR SEDATIVES

Active euthanasia and assisted suicide can be distinguished from providing high doses of opioids or sedatives to relieve severe pain in patients with terminal illness or to relieve dyspnea when patients forego mechanical ventilation (1). As Chapter 14 discusses, the appropriate goal of care in these situations is to relieve suffering. In rare cases the dose required to relieve distress might hasten death. Concerns about active euthanasia and assisted suicide should not deter physicians from providing aggressive palliative care (6). Indeed, fears that terminal distress will not be adequately relieved impel some patients to seek active euthanasia and assisted suicide (7,8).

REASONS IN FAVOR OF ASSISTED SUICIDE AND ACTIVE EUTHANASIA

Proponents of these acts offer several justifications for their position (9,10).

RESPECT FOR PATIENT AUTONOMY

The prospect of a long, debilitating illness that would destroy their sense of identity and dignity horrifies many persons. People might fear loss of privacy and increased dependence on others for basic needs such as feeding, bathing, and toilet use. They also might not want their family and

friends to remember them as progressively debilitated. Proponents contend that competent patients with terminal illness should have control over the time and manner of their death. In this view it is inconsistent to permit patients to end their lives by refusing medical interventions after a complication occurs but not to end it more directly beforehand.

COMPASSION FOR PATIENTS WHO ARE SUFFERING

Some argue that assisted suicide and active euthanasia show compassion for patients in the final stages of a terminal illness. Many people regard it as inhumane to require such patients to suffer a downhill course while waiting to die of complications. As one author put it, "People who want an early peaceful death for themselves or their relatives are not rejecting or denigrating the sanctity of life; on the contrary, they believe that a quicker death shows more respect for life than a protracted one (11)." Some terminally ill patients have refractory symptoms despite optimal palliative care. For example, some patients with cancer of the esophagus or head and neck cannot swallow their secretions, some patients with acquired immunodeficiency syndrome suffer refractory diarrhea, and some cancer patients experience intractable bleeding. Such patients can be sedated so that they are no longer conscious of their symptoms, but they will not have dignified or peaceful deaths.

Proponents of assisted suicide also argue that physicians cannot prevent people from killing themselves; they can only alter the means by which patients end their lives. If lethal drugs are not available, patients might resort to hanging or guns. Such means of death are gruesome and distress family members and friends. Advocates contend that terminally ill patients should have a more humane means of ending their lives.

REASONS AGAINST ASSISTED SUICIDE AND ACTIVE EUTHANASIA

Traditional codes of medical ethics prohibit physician participation in assisted suicide or active euthanasia (12–14). Active euthanasia is illegal in all states, and most states explicitly prohibit assisted suicide.

THE SANCTITY OF LIFE

Many people assert that assisted suicide and active euthanasia demean the sacredness of human life and violate fundamental moral prohibitions against killing human beings.

SUFFERING CAN ALMOST ALWAYS BE RELIEVED

Palliative care is often inadequate in terminally ill patients. Opponents fear that assisted suicide and active euthanasia will allow physicians to avoid the difficult task of providing physical and spiritual comfort to dying patients. Some people suggest that suffering can be redemptive and that patients have a duty to endure it or cope courageously (13).

REQUESTS FOR ASSISTED SUICIDE ARE NOT AUTONOMOUS

Most terminally ill patients change their minds on suicide after receiving better palliative care or treatment for depression. Thus, their initial requests may not be truly autonomous. Physicians have an ethical obligation to prevent suicide because the vast majority of patients who attempt suicide have a psychiatric illness, such as major depression, that can be treated (*see* Chapter 40). Even among patients with cancer, most suicidal individuals are clinically depressed, and major depression can be treated (15,16).

FEARS OF ABUSE

A slippery slope might occur: If physician-assisted suicide is permitted for competent terminally ill patients, it is logically inconsistent to prohibit it for patients who are not competent or not terminally ill or to prohibit active euthanasia. For example, if competent patients have a right to physician-assisted suicide, it would be inconsistent to deny it to patients who have previously requested it but have lost decision-making capacity. A patient with mild Alzheimer disease might not want to live if he or she could no longer recognize his or her family. At that stage, however, the patient would no longer be capable of making an informed request. Thus, if the patient is not permitted to request physician-assisted suicide or active euthanasia through an advance directive, the patient would face a cruel dilemma: to end life when it is still meaningful or to live in an unacceptably dehumanized condition. Furthermore, some patients with severe amyotrophic lateral sclerosis (ALS) might want to hasten their death to avoid further dependency and to relieve their suffering. However, such patients are not terminally ill and might lack the physical ability to ingest medication without assistance. Thus, respecting their wishes to hasten death might require active euthanasia.

A second type of slippery slope might also occur. At first, physicians who participate in assisted suicide might carefully ensure that every case is appropriate, but over time they might become less diligent in providing palliative care or checking that the patient's request is voluntary. Eventually, assisted suicide might occur when palliative care was grossly inadequate or major depression was unaddressed.

Active euthanasia raises particular fears about abuse. Euthanasia for competent patients logically leads to euthanasia of patients who lack decision-making capacity. Furthermore, relief of unbearable suffering might be used to justify active euthanasia in mentally incapacitated patients who had never requested it. Another fear is that pressures to control health care costs will result in nonvoluntary euthanasia of persons whose care is regarded as too burdensome or too expensive (17). Patients with chronic illness or disability might feel pressured by family members or physicians into terminating their lives.

THE PHYSICIAN'S ROLE

Opponents argue that active euthanasia and assisted suicide are incompatible with the physician's role as healer. In this view patients would lose trust in physicians if these practices were permitted. In one study, 19% of oncology patients said they would change physicians if their physician told them they had provided active euthanasia or physician-assisted suicide for other patients (18).

LEGALIZATION OF PHYSICIAN-ASSISTED SUICIDE IN OREGON

In Oregon, terminally ill, competent adults may request medication to end their lives (19,20). The patient must make a written request that is witnessed by two people who attest that the patient is competent, acting voluntarily, and not coerced. Fifteen days after this written request, the patient must repeat the request orally. An additional 48 hours must elapse before the prescription can be filled. The patient may rescind the request at any time. Physicians must ensure that patients are informed about their diagnosis, prognosis, and therapeutic alternatives, such as palliative care. A consultant must confirm that the patient has a terminal disease, is capable of making health care decisions, is informed, and is acting voluntarily. Patients with a psychiatric disorder that impairs judgment must be referred for counseling. Physicians who comply with the provisions of the law are granted legal immunity from criminal, civil, and professional disciplinary actions. Physicians and other health care workers may refuse to participate. If a patient ingests a lethal dose of medication under this law, life insurance policies are not voided. Several groups of patients fall outside this law's coverage. The law specifically prohibits active euthanasia, mercy killing, and lethal injection. Physicians are not allowed to provide assistance to patients who are too incapacitated to take lethal medication themselves. Patients are excluded if they suffer from nonterminal illnesses, lack decision-making capacity, or are too sick to survive the waiting periods. Patients may not request suicide assistance through advance directives or surrogate decision-makers.

In Oregon, 9 deaths per 10,000 are cases of physician-assisted suicide reported to the state (21,22). Compared to other terminal patients, these patients were more concerned about loss of autonomy and loss of control over bodily functions because of their illness (22). Poverty, lack of education or health insurance, or poor quality of care did not play a major role in the patient's decision (23). Over two thirds of these patients did not receive the requested prescription from the first doctor they asked (23). Some physicians who participated in physician-assisted suicide reported a large emotional toll (22).

THE PRACTICE OF PHYSICIAN-ASSISTED SUICIDE AND ACTIVE EUTHANASIA

Despite legal prohibitions, physician-assisted suicide and active euthanasia are practiced in the United States.

REQUESTS FOR PHYSICIAN-ASSISTED SUICIDE AND ACTIVE EUTHANASIA ARE COMMON

In a national sample, 18% of physicians said that in their careers they had received a request for physician-assisted suicide and 11% said they had received a request for active euthanasia. In another study over 50% of oncologists had received a request for physician-assisted suicide and 38% had received a request for active euthanasia (24). Twelve percent of cancer patients said they had serious discussions about active euthanasia or physician-assisted suicide with their family or physician, and 3.4% said they hoarded drugs (24).

REQUESTS ARE MORE COMMON IN DEPRESSED PATIENTS

Nineteen percent of patients who received physician-assisted suicide and 39% of patients who received active euthanasia were depressed (2). In another study cancer patients who were depressed were 4.6 times more likely to have discussed euthanasia (24).

PHYSICIANS PROVIDE REQUESTED ASSISTANCE EVEN WHEN IT IS ILLEGAL

Among physicians, 3.3% had written a prescription to be used to hasten death and 4.7% had administered a lethal injection (2). Among oncologists, 13% had assisted suicide and 1.8% had performed active euthanasia.

PHYSICIANS ARE CONFUSED ABOUT WHAT CONSTITUTES PHYSICIAN-ASSISTED SUICIDE AND ACTIVE EUTHANASIA

In some cases that physicians characterized as physician-assisted suicide or active euthanasia, it would be accurate to describe the situation differently. For example, in 13% of cases physicians actually provided high doses of opioids for pain relief; such palliation of symptoms is ethically distinct from assisted suicide or active euthanasia. In another 9% of cases, patients overdosed without asking the physician for a prescription for a lethal dose; this cannot be described as physician-assisted suicide or active euthanasia (18). Furthermore, 12% of physicians who said that they had assisted suicide actually ordered a nurse to inject medications to end the patient's life; it would be accurate to characterize this action as active euthanasia (18).

PROPOSED SAFEGUARDS ARE OFTEN VIOLATED

When physicians prescribe a prescription for physician-assisted suicide, suggested safeguards, such as persistent requests and second opinions, are often not followed. In two studies patients repeated their request in only 51% and 60% of cases and doctors obtained a second opinion in only 1% and 40% of cases (2,18).

In 54% of cases of active euthanasia, a family member or partner rather than the patient made the request (2). A second opinion was obtained in only 32% of cases. In 94% of cases immediate assistance was requested.

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PATIENTS FREQUENTLY DO NOT USE PRESCRIPTIONS FOR LETHAL DOSES OF MEDICATION

Approximately 40% of patients who receive prescriptions for lethal doses of medication do not use them (2,25). Presumably the prescription provided reassurance that the patient was in control of the final days.

PHYSICIAN-ASSISTED SUICIDE HAS AN EMOTIONAL IMPACT ON THE PHYSICIAN

In one study, 18% of physicians who had assisted suicide were uncomfortable doing it (2). In another study, although 53% of respondents were comfortable assisting suicide or performing active euthanasia, 24% regretted performing them (18).

LEGALIZATION OF ASSISTED SUICIDE AND ACTIVE EUTHANASIA IN THE NETHERLANDS

In the Netherlands active euthanasia and assisted suicide are legal in certain situations (26). A competent patient with a terminal illness must make a voluntary and persistent request for active euthanasia or assisted suicide, and two physicians must certify that the patient is terminally ill. In the Netherlands active euthanasia occurs in between 2.3% and 2.4% of deaths and assisted suicide occurs in between 0.2% and 0.4% (27).

MOST PATIENTS WITHDRAW THEIR REQUESTS FOR EUTHANASIA OR ASSISTED SUICIDE

Patients' requests for active euthanasia or assisted suicide usually do not last. When patients ask physicians to help them die, only one third of requests are serious and persistent. Of these, only one third actually receive active euthanasia or assisted suicide; most change their minds after obtaining better palliative care. Thus, only 11% of patients who initially request active euthanasia or assisted suicide accept it later (28).

PROCEDURAL SAFEGUARDS ARE VIOLATED

In 0.7% of deaths physicians ended the patient's life without the patient's explicit, concurrent request (27). In about one half of these cases, the patient had discussed these decisions previously with the physician. In a few cases, however, the physician did not discuss these actions with anyone, including relatives or colleagues.

CONSEQUENCES FOR SURVIVORS

Family and friends of cancer patients who died by euthanasia had fewer symptoms of traumatic grief and fewer posttraumatic stress reactions than family and friends of patients who died of natural causes (29).

UNINTENDED CONSEQUENCES

When patients attempted physician-assisted suicide, technical problems occurred in 10% of cases, most commonly difficulty swallowing the pills. Complications occurred in 7%, most commonly nausea and vomiting. In 18% of cases a physician administered a lethal drug, most commonly because the patient did not die or did not die as soon as expected. When physicians attempted active euthanasia, technical problems occurred in 5% of cases, most commonly difficulty finding a vein. Complications occurred in 3% of cases, most commonly spasm and myoclonus. In 5% of cases death did not occur or took longer than expected (30).

POLICY OPTIONS

Several public policies are possible about physician-assisted suicide and active euthanasia. One option is to continue traditional prohibitions. However, these practices occur even though they are illegal. Abuses might be more likely to occur if decisions remain secret than if they are discussed openly. Furthermore, prosecutors are reluctant to bring charges against physicians who convincingly assert that they were relieving the patient's suffering, and juries are reluctant to convict such doctors. This discrepancy between the law in the books and the law in practice is problematic because enforcement might be inconsistent or biased (6). A second option is to legalize these practices under certain conditions, such as in Oregon. The challenge is whether effective safeguards against abuses can be developed. A third option is to keep active euthanasia and assisted suicide illegal but to acknowledge that in exceptional cases, such practices might be ethically justified and legally condoned (31). The risk of legal sanctions would help deter these actions in questionable or inappropriate cases.

HOW SHOULD PHYSICIANS RESPOND TO REQUESTS FOR ASSISTED SUICIDE OR ACTIVE EUTHANASIA?

Physicians must be prepared for questions from patients on assisted suicide or active euthanasia. Like the general public, doctors disagree over the morality of these controversial actions (2). Regardless of their personal views, physicians can respond in certain ways (Table 19-1) (32-35).

FIND OUT THE REASONS FOR THE REQUEST

Why is the patient asking a question or making a request at this time? A request or question might represent a response to unrelieved suffering, a demand for more control, emerging psychosocial problems, a spiritual crisis, or a fear of abandonment (33,36). Requests might be triggered by loss of dignity, pain, and dependence on others (28). Only rarely is pain the sole reason for a patient's request. Physicians also need to screen patients for major depression, which can be treated even in terminally ill patients (16).

Some physicians fear that talking about assisted suicide or active euthanasia will encourage patients to carry out these acts. Such fears are unfounded. Most terminally ill patients have already thought about these issues and feel relieved that physicians are willing to discuss them. Suicidal patients with terminal illness deserve the same careful evaluation and mobilization of resources as patients who are not terminally ill (37).

PROVIDE MORE INTENSIVE PALLIATIVE CARE

If their suffering or concerns are addressed, most patients find life worth living. Pain relief can be improved through using higher and more frequent doses of opioids, administering them on a regular schedule rather than as needed, and giving patients more control over dosage. In addition to alleviating physical suffering, physicians can help patients come to terms with their mortality and to find meaning in the final stage of their lives. Instead of immediately trying to resolve problems or reassure patients, doctors can explore the patient's suffering using open-ended questions and empathic

TABLE 19-1

Responding to Requests for Assisted Suicide or Active Euthanasia

Find out the reasons for the request.
Provide more intensive palliative care.
Reaffirm patient control over treatment decisions.
Do not impose your values on patients.
Consult a trusted and wise colleague.

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comments: "That sounds very distressing. Can you tell me more? (38)." Attentive listening validates the patient's emotions and shows the patient that he or she has been understood. The physician should consult with palliative care specialists, psychiatrists or psychologists, social workers, chaplains, and hospice workers as needed. Physicians also can arrange hospice-type home care, mobilize family members and friends, and be available during patients' final weeks and days.

REAFFIRM PATIENT CONTROL OVER TREATMENT DECISIONS

Some patients might seek to hasten death because they fear they will be subjected to unwanted life-prolonging interventions. Physicians need to reassure patients that their decisions to forego life-sustaining interventions will be respected.

DO NOT IMPOSE YOUR OWN VALUES ON PATIENTS

Proponents of assisted suicide should not write a lethal prescription on request without evaluating the patient for depression and inadequate palliative care. Conversely, opponents of these actions should not denigrate the patient's request but rather communicate empathy and compassion for the patient's plight.

CONSULT A TRUSTED AND WISE COLLEAGUE

Most physicians find patient requests for assisted suicide or active euthanasia to be highly stressful. As with any other difficult case, a second opinion or discussion with a colleague is generally helpful. Often, a colleague can suggest how to improve palliative care or how to talk with the patient.

DECLINING TO GIVE ASSISTANCE

Physicians should not participate in assisted suicide or active euthanasia against their conscience or religious beliefs. When communicating their refusal, physicians need to elicit and address the patient's concerns and show empathy for the patient's plight. The physician might say, "I hear that you are deeply distressed by your illness. I'll try my best to relieve your suffering. But I can't help you kill yourself. My conscience won't allow me to do that." Such physicians need to emphasize their commitment to provide ongoing palliative care.

SITUATIONS IN WHICH ASSISTED SUICIDE MIGHT BE JUSTIFIED

Many physicians can conceive of a case in which they would consider assisted suicide morally permissible (39). The following circumstances would constitute the strongest case for agreeing to a patient's request (9,10).

- *The patient has a terminal illness* or a progressive, incurable condition causing unrelenting suffering, such as ALS.
- *The patient is experiencing intractable symptoms* despite optimal palliative care. Even the best palliative care cannot relieve intractable bleeding or inability to swallow secretions. Actual distress is more compelling than anticipated future symptoms. Many physicians are more sympathetic to patients with physical distress than to patients with mental distress. The distinction between physical and mental suffering might be philosophically untenable, but it is helpful for pragmatic reasons because mistakes and abuse are less likely with physical distress.
- *The patient's request is voluntary, informed, and repeated.* Ideally, the patient raises the issue and is willing to discuss it with family members, friends, or clergy.
- *The physician has a long-term relationship with the patient* that started before the patient requested assistance with suicide.
- *The physician has obtained second opinions* about the adequacy of palliative care and the absence of depression.

In the rare cases in which these conditions are present, it is ethical for physicians to assist in suicide.

Active euthanasia is more problematic because it presents greater potential for abuse. Although requests by surrogates for active euthanasia are usually motivated by compassion, surrogates might confound their own values and desires with those of the patient. They might interpret a gesture or a look as an unspoken request to hasten death, saying, for example, "I looked into his eyes and I just knew what he was asking me to do." The risk of projection, misinterpretation, and abuse are great in this situation. Prohibiting active euthanasia for patients who lack decision-making capacity is sound public policy.

In conclusion, it should never be easy for a physician to respond to the request of a patient who is dying in great suffering despite good palliative care. Even in the most compelling case, decisions will be difficult and conscientious and reasonable persons will disagree. Ultimately, physicians will find answers in their own conscience, personal morality, and religious beliefs. Regardless of the physician's decision, however, patients deserve an honest answer to their questions or request. More important, physicians must demonstrate their dedication to relieving suffering and their willingness to be with patients during the process of dying.

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Two well-designed empirical studies elucidating the practice of physician-assisted suicide and active euthanasia in the United States despite legal prohibitions.

The Persistent Vegetative State

Because they are breathing and their hearts are beating, patients in the persistent vegetative state (PVS) are alive. However, they are not aware of their environment and cannot respond to other people or communicate with them. Although PVS is uncommon, the cases of Karen Ann Quinlan, Nancy Cruzan, and Theresa Schiavo, patients in PVS, dramatized fundamental questions about the goals of medicine and the definition of being a person.

This chapter describes the clinical features of PVS, discusses some of the philosophical quandaries it presents, and analyzes appropriate justifications for limiting life-prolonging interventions for patients in this condition.

CLINICAL FEATURES

DEFINITION OF VEGETATIVE STATE

Patients in a vegetative state have no cortical function but have preserved brainstem function. As far as can be determined, they are unconscious, with no awareness of their environment (1,2). They show no purposeful activity and cannot obey verbal commands. Because their cortical structures have been destroyed, they cannot experience pain. However, it is important for physicians and family members to appreciate that some neurologic functions are maintained. "Vegetative" functions, such as breathing and circulation, remain intact. Thus, patients in a vegetative state usually do not require mechanical ventilation. In addition, these patients are not comatose because they have cycles of sleeping and waking. While they are awake, their eyes might be open. Roving eye movements are present, and tracking might occasionally occur. Reflexes such as sucking, chewing, and swallowing might also be present. Pupillary, oculocephalic, and deep tendon reflexes are sometimes preserved. Patients might withdraw or posture in response to noxious stimuli and startle and turn in the direction of sudden loud noises. Such patients might grunt, grimace, smile, and produce tears. Because of these preserved neurologic functions, some observers believe that patients in a vegetative state are aware of their surroundings or have responded to them. Some observers might claim that the patient watched them cross the room or cried when they talked to them. Other observers at other times, however, cannot replicate these "responses" in any consistent manner.

The diagnosis of a vegetative state requires repeated examinations by an experienced neurologist. The diagnosis is clinical, and diagnostic tests are not essential. Positron-emission tomography scans in patients in a PVS show low brain metabolism, similar to what is seen in patients under general anesthesia.

DEFINITION OF PERSISTENT VEGETATIVE STATE

A PVS is defined as a vegetative state that has lasted 1 month (1). In the United States about 10,000 to 25,000 adults and 4,000 to 10,000 children currently are in a PVS (1,2). A crucial issue is determining when a PVS has become permanent.

Prognosis for recovery of consciousness can be accurately established only after the patient has been in a vegetative state for some time (1). The required time of observation will depend on the etiology. After nontraumatic injury, such as anoxic brain damage during a cardiac arrest, very few patients awaken after 3 months. After trauma, patients rarely awaken after 12 months in a vegetative state.

No intervention has been shown to be effective in restoring consciousness. In a few well-documented cases, patients in true PVS have recovered consciousness more than 3 months after anoxic injury or more than 12 months after traumatic injury (1,3). Patients who recover consciousness have moderate or severe residual neurologic impairments.

The mean survival of patients in a PVS is 2 to 5 years. A few patients have been reported to survive longer than 15 years. Patients in a PVS require tube feedings because they are unable to swallow and protect their airway. They are incontinent and require total nursing care. Common complications are decubitus ulcers, aspiration pneumonia, and urosepsis.

PVS needs to be distinguished from other catastrophic neurological conditions. In *brain death* there is neither cortical nor brainstem function (see Chapter 21). Thus, the electroencephalogram (EEG) shows no activity. In the *locked-in syndrome* patients are conscious but have no motor function. Such patients might be able to communicate by blinking their eyes. Patients with *severe dementia* might be virtually unresponsive, but they are conscious and might have some motor function. The term *minimally conscious state* has been used to describe patients who are conscious but have severe neurologic impairments. The term is best avoided because it cannot be defined precisely (4).

Misunderstandings about PVS are common. Despite extensive clinical evidence that patients in a PVS lack the cortical capacity to be conscious of pain (1), 25% of neurologists believed that patients in a vegetative state experience feelings of pain and 22% believed that such patients are more comfortable with tube feedings (5).

WHAT TREATMENT IS APPROPRIATE?

Many persons would be horrified to be kept alive if there were virtually no likelihood of regaining consciousness. To them, life as a "vegetable" is a fate worse than death. They would reject tube feedings and other interventions.

A more radical and controversial position is that all medical interventions should be withheld or withdrawn from patients in a PVS because they have lost the essential characteristics of being a person, which include consciousness and the ability to have social interactions and to respond. In this view it is not merely *permissible* to withdraw tube feedings from patients in a PVS but *mandatory* to do so (6,7).

In contrast, other people believe strongly that persons in a PVS should receive life-prolonging interventions. Some family members do not believe that the patient is unconscious, claiming that the patient responds to them. Others reject the prognosis, believing that the patient will recover despite unfavorable odds. Still others believe a life without consciousness remains sacred. In their view it would violate human dignity to forego basic care such as feeding tubes and antibiotics, which allow patients to survive for years and have few adverse effects (8).

MEDICAL INTERVENTIONS MAY BE WITHHELD OR WITHDRAWN

As Chapter 13 discussed, when patients lack decision-making capacity, interventions ranging from cardiopulmonary resuscitation (CPR) to antibiotics for infection may be withheld on the basis of advance directives or decisions by appropriate surrogates (1,2).

It is worth noting how a consensus has developed since the 1976 Karen Ann Quinlan case (see Chapter 22). In that case the issue was whether to discontinue a ventilator (at the time, doctors did not know that patients in a PVS do not require ventilatory assistance). In recent cases decisions to

withhold CPR from patients in a PVS were not challenged. More recent controversies have focused on whether feeding tubes should be regarded differently from other medical interventions.

TUBE FEEDINGS ARE A MEDICAL INTERVENTION, WHICH MAY BE WITHHELD OR WITHDRAWN

Some people consider feeding tubes "ordinary" nursing care that must always be provided. However, feeding tubes have benefits and burdens that must be assessed for the individual patient. As Chapter 18 discussed, it is permissible to withhold or withdraw tube feedings from persons in a PVS, in accordance with the patient's prior directives or best interests (1,9,10). In practice, many people are ambivalent about tube feedings in PVS. In a survey of neurologists, 88% believed that it is ethical to forego artificial nutrition in PVS; however, 47% also believed that artificial nutrition should generally be provided.

Controversies over interventions in a PVS are not technical issues to be decided solely by physicians. Value judgments on the definition of a human being are unavoidable. Ultimately these issues are not susceptible to logical proof or refutation. They can be resolved only by appealing to deeply personal or religious beliefs. These beliefs might lead people to strikingly different conclusions about appropriate care of patients in a PVS.

In summary, physicians need to understand the clinical features of PVS and the criteria for diagnosing it. Many ethical dilemmas regarding PVS can be resolved by applying guidelines for decisions in patients who lack decision-making capacity. It is permissible to withdraw feeding tubes and other interventions in accordance with advance directives or decisions by appropriate surrogates.

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Documents widespread misconceptions about PVS among physicians.

Determination of Death

Before the development of intensive care, patients were declared dead when breathing and circulation stopped. However, such traditional concepts of death are now problematic because a patient's breathing and circulation can be sustained on life support after all cerebral functions have been permanently lost. Thus, criteria for brain death have been developed and are widely accepted. Accurate and consistent determinations of death are essential because declaring a patient dead has profound emotional and practical consequences (1–3). Mourning commences and funeral services are held. Dead persons are buried or cremated. Their organs might be removed for transplantation. Their spouses might remarry, pensions and health insurance coverage are terminated, their properties pass on to heirs, and their life insurance policies are paid. Defining death is controversial because it involves cultural, social, and religious values, as well as scientific judgment. Furthermore, discussions are complicated by frequent misunderstandings about brain death.

This chapter discusses ethical issues regarding traditional, whole-brain, and higher brain criteria for death.

PROBLEMS WITH CARDIOPULMONARY CRITERIA FOR DEATH

In the absence of artificial life support, brain function ceases minutes after cessation of heartbeat and breathing. With the development of intensive care units (ICUs), however, circulation and breathing can be sustained for months even though the brain has irreversibly ceased to function and the patient will never recover. Most people believe it would be pointless to sustain vital functions in such a situation.

Organ transplantation has also raised ethical issues about the declaration of death. Transplantation of vital organs, which is potentially life-saving to recipients, cannot be performed without clear agreement that the organ donor has died. Transplant teams want to retrieve organs as soon as possible. On the other hand, relatives and the public want assurance that organs are not harvested prematurely from persons who are not truly dead.

Disputes about the determination of death might also arise with persons on whom criminal acts were committed. Some defendants in murder trials have contended that the person's death was caused by discontinuation of life-sustaining treatment, not by their actions (4).

Because of these problems with traditional cardiopulmonary criteria for death, the definition of death was revised to include absence of brain function, also known as brain death.

THE CONCEPT OF BRAIN DEATH

Patients who have permanently lost all brain function are considered dead, even though medical technology supported their circulation and breathing. Brain death is defined as irreversible loss of functioning in the entire brain, both cortex and brainstem. This is also called *whole-brain death*.

Brain death is tantamount to "permanent cessation of the functioning of the organism as a whole" (5). Because the brain is the coordinating and integrating center of the body, death of the brain ensures that the organism as a whole can no longer function. Destruction of the brain generally leads to cessation of spontaneous cardiac function within a week (6).

Currently, the clinical tests for brain death include coma, absence of brainstem function, and apnea (7). Potentially reversible, confounding causes of coma, such as drug overdose or hypothermia, must be ruled out. Circulation and spinal cord reflexes might be intact in brain death. Confirmatory testing with an electroencephalogram (EEG) or angiography might be helpful but is not required. In children the determination of brain death is more complicated because prognosis is more difficult to establish (8,9).

In recent years these criteria for brain death have been questioned. In some brain-dead patients, there might be persistence of some cerebral blood flow, oxygen and glucose metabolism, EEG activity, brainstem-evoked potentials, and secretion of antidiuretic hormone (10). Moreover, spontaneous body movements generated by the spine might be present (7). In exceptional cases there might be a substantial discrepancy between determinations of death using brain death criteria and traditional cardiopulmonary criteria. Several pregnant women meeting brain death criteria had their vital functions sustained for months until the fetus could be delivered (11).

CONTROVERSIES OVER BRAIN DEATH

There is widespread confusion over brain death (12). Only 35% of physicians who were responsible for declaring death were able to identify irreversible loss of all brain function as the criterion for determining death and apply it to simple case vignettes. Among other health care workers involved in the care of persons declared brain dead, over 70% were unable to identify the legal and medical criteria for brain death. When asked to explain their personal opinions about two case vignettes, 58% of all respondents did not consistently use a coherent concept of death. Thirty-six percent believed that it is appropriate to retrieve organs from a patient in a vegetative state who does not meet criteria for whole-brain death. Moreover, hospital policies on criteria for brain death vary considerably and might not be consistent with expert guidelines (13,14).

Whole-brain death criteria have been criticized for being both too narrow and too inclusive. These controversies illustrate the impact of cultural, social, and religious values on the definition of death.

HIGHER BRAIN DEATH

Some writers argue that a person should be considered dead if there is irreversible loss of higher brain function in the cerebral cortex rather than loss of whole-brain function (15). These writers argue that consciousness, self-awareness, the potential for thought, and interactions with others are essential for being a person (16). However, most writers reject a "higher brain" or neocortical definition of death (17). Reliable clinical tests for higher brain death are not available. The concept of higher brain death seems to confuse what it means to be a person with what it means to be alive. It might be appropriate to say that individuals without cortical function are no longer persons in the philosophic sense of having rights and interests. However, it does not follow logically that they should be considered dead. Finally, higher brain criteria contradict deeply held beliefs about death. Burying or cremating individuals in a persistent vegetative state or with severe dementia, who have no cortical function but who are still breathing and have a pulse, seems intuitively wrong.

DISAGREEMENT ON THE CONCEPT OF BRAIN DEATH

Some persons reject the concept of brain death for religious or philosophic reasons (18,19). For example, some orthodox Jews, Native Americans, and Japanese believe that a person is alive until he or she literally stops breathing (20). No distinction is made between mechanical ventilation and spontaneous breathing. In this view a person on a ventilator who meets the standards for brain death is not dead.

LEGAL STATUS OF BRAIN DEATH

Most states have adopted the Uniform Determination of Death Act, which declares, "Any individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards (4)." Thus, a person may be declared dead if he or she meets either cardiopulmonary criteria (absence of breathing and pulse) or brain death criteria. For most patients who are not on life support, these two criteria are equivalent.

Two states defer to patient beliefs about the definition of death. New Jersey authorizes the declaration of brain death, except in cases in which the physician has "reason to believe" that "such a declaration would violate the personal religious beliefs of the individual (21)." For such individuals death must be declared according to traditional cardiorespiratory criteria. Similarly, New York requires "reasonable accommodation of the individual's religious or moral objection" to brain death criteria (22).

PRACTICAL SUGGESTIONS ON BRAIN DEATH

An experienced neurologist should be consulted before a patient is declared brain dead. Once brain death has been determined, relatives need to be told. Such discussions require sensitivity and patience. Some family members might believe the patient will regain consciousness, particularly if the death was sudden or unexpected. In almost all cases compassionate explanations and emotional support from health care workers help the family accept the situation.

If organ transplantation is feasible, a physician not associated with the transplantation team should declare death, so as to avoid even the appearance of conflict of interest (23,24). Discussion of the possibility of organ donation with the survivors should wait until after the declaration of death, unless the family first raises the issue.

After a patient has been declared dead by brain death criteria, all life-sustaining interventions should be discontinued, with certain exceptions. Maintaining life support might be appropriate until family members can come to the hospital, until organs for transplantation can be harvested or, under exceptional circumstances, until a fetus can be delivered.

In summary, the development of intensive care and organ transplantation has made traditional definitions of death untenable in some cases. Physicians need to understand the clinical criteria for brain death and controversies over the concept. Ultimately the definition of life and death depends on cultural, social, and religious beliefs as well as medical expertise.

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Legal Rulings on Life-Sustaining Interventions

Dramatic legal cases regarding life-sustaining interventions have received prominent news coverage. These landmark court rulings have shaped clinical practice and have motivated people to discuss their preferences for such interventions.

THE QUINLAN CASE

In 1976 the Karen Ann Quinlan case dramatized the dilemma of whether it might be more humane to withdraw life support rather than to prolong life when there is no hope of regaining consciousness (1).

THE CASE

Karen Ann Quinlan was a 22-year-old woman in a persistent vegetative state (PVS) because of an unknown illness. Her physicians agreed that she would never regain consciousness. She was on mechanical ventilation, and her physicians believed that she would die if the ventilator were withdrawn. Her father, after consulting with his priest and the hospital chaplain, asked that the ventilator be withdrawn. When the physicians refused, he asked the courts to appoint him Karen's legal guardian with the authority to terminate the ventilator. The Catholic bishops of New Jersey supported his request.

THE COURT RULING

The New Jersey Supreme Court ruled that Karen Ann Quinlan's right to privacy included a right to decline medical treatment and that her father as guardian could exercise this right on her behalf. Her guardian and family should be permitted "to render their best judgment" as to whether she would have chosen herself to decline treatment.

The court held unanimously that if Karen's guardian and family, her attending physician, and a hospital "ethics committee" agreed that "there is no reasonable possibility" of recovering a "cognitive and sapient state," the ventilator may be withdrawn. In advocating hospital ethics committees, the court wrote, "In the real world and in relationship to the momentous decision contemplated, the value of additional views and diverse knowledge is apparent (1)." No party would face any civil or criminal liability for discontinuing the ventilator. The court also declared that generally such decisions need not be brought to court "not only because that would be a gratuitous encroachment upon the medical profession's field of competence, but because it would be impossibly cumbersome."